

Hannah's Story

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Abstract

This is the story of my daughter, Hannah. Hannah is an amazing child. She can speak, read, and write English. She can play the piano and violin and she is mainstreamed into a third grade class. Hannah was born profoundly deaf and was not diagnosed until she was almost two years old. She received a cochlear implant when she was 2 ½ years old. Through a lot of support, therapies, and perseverance, the goals that her parents set up for her were achieved. Hannah is not only amazing for accomplishing these goals, she is amazing because as her parents were teaching her to speak and read, she was teaching her parents about courage, strength, and love.

Keywords

cochlear implants, inclusion, deafness

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To this day, people ask us how we couldn't have known that Hannah was deaf, since she was 22 months old when she was diagnosed. I wonder if we were in denial or just in bliss being first time parents. We never confronted the idea of a hearing loss, and since Hannah was our first, we did not have a comparison to a typical hearing child. She was bright, developing appropriately, and beautiful. She was very social, and being the only child in the home, one of us was always communicating with her face to face. Hannah was babbling the age appropriate sounds. She called me "Mama" and my husband "Baba."

At around 18 months, we started to be concerned about the lack of more sophisticated language development. At her 18 month well-baby visit, I brought up my concerns, but at this time she had an ear infection and her doctor thought that it was possible that she had a fluid retention problem that could have been present for many months. We needed to wait for the infection to clear up before proceeding with a tympanometry test. This test assesses the pressure in the middle ear and it may be helpful to detect fluid, problems with the middle ear, and other conditions. When that test came up negative, our fears were alleviated for a short time. However, after another couple of months, our concerns grew greater. We decided to have an audiogram done to determine if Hannah had a hearing problem. Our first trip into the sound booth was not very successful. Hannah was afraid of the booth and buried her head into my husband's shoulder. The test was deemed inconclusive which led to more waiting. Another test was attempted a short time later, but that was also inconclusive. Finally, it was suggested that Hannah have an Auditory Brainstem Response. This test involves sophisticated computer equipment. Sounds are placed in the ear and the brainstem's response is re-

corded from electrodes that are taped to the patient's head. Hannah was sedated for this test. We waited patiently throughout the test, hoping that one of the technicians would give us an idea of the results, but they would not. We were told that we would have results within two weeks. I should have known that something was wrong when our family doctor called that afternoon. He told us that Hannah had little or no response to the test. This was a clear diagnosis, our child was profoundly deaf.

To say that our world turned upside down is an understatement. Our lives were clearly in chaos, but Hannah's world remained the same as it was before the test. We had just found out the child that we thought was "normal," never heard our voices, never heard music, and didn't experience life the way that we thought she had. But for Hannah, life was the same as always. She was still a happy little girl that had experiences that were full of activity, sight, and touch. These were part of an inner life that was not always something that we were a part of. We knew that our next step in this process was to find out the exact extent of Hannah's hearing loss. While researching the topic, we found that the level of the child's residual hearing would impact the amount of speech and language that he or she would be capable of. We were back to the sound booth with an even more uncooperative child. Hannah was still afraid of the booth, but I'm sure that our anxiety was not helping her relax in this environment.

She was evaluated out of the sound booth by a teacher of the deaf and a speech therapist. They were evaluating Hannah's sound awareness and also paying attention to her cognitive abilities. It seemed apparent in this evaluation that Hannah was not hearing any sounds, but had a willingness to communicate. After the results were received from

these professionals, we quickly set up services for her. She began receiving speech services and seeing a teacher of the deaf. Though the therapists were knowledgeable and caring, they made it clear to us that the communication method for Hannah was our decision. Here we were faced with a new set of choices. Should we sign to our daughter or try an oral approach? Should we have her fitted with hearing aids or research new hearing technology? Should we move to an area where there was a larger Deaf population with more services available, or look into mainstreaming in our own district? The choices were endless and frustrating.

One of the aspects of this journey that I was unprepared for was the raging controversy within the Deaf community. I was unaware that there was a cultural debate happening between the hearing and the deaf. Three in 1,000 babies are born with a hearing loss each year in the United States. The hearing loss can range from mild to profound. The loss can be caused by trauma, genetics, illnesses, or exposure to different drugs. 90% of these children are born to hearing parents. Many in the Deaf community feel that these children born to hearing parents should be raised in a deaf environment with deaf peers and mentors. Partly because a distinct language, (American Sign Language) exists, they look at deafness as a cultural difference rather than a disability. We were of the philosophy that it would be difficult to teach a language we were not fluent in, and would never want to turn this responsibility over to others. Our goal was to communicate with Hannah as quickly as we could and begin teaching her the English language. Learning to read and write English was a must; learning to speak was a secondary goal.

Hannah was participating in speech therapy and communication therapy with a

teacher of the deaf. This therapy was really for the whole family as my husband and I were learning about sign language, listening therapy, and communication for the hearing impaired. A casual onlooker would have thought that the therapists were playing with her, but all of the games were communication and vocabulary enhancers. Since she had no verbal vocabulary, it would have made little sense to call a toy airplane an "airplane." Instead she (and we) were taught the sign for airplane and also the accompanying "listening sound." In this case the sound was "aaaaahhh" as you were signing or pretending to fly the airplane in the air. We were also learning sign language from a sign dictionary. The signs are based on the alphabet and a precursor to primary vocabulary for young signers.

When we expressed to our service providers that our main goal at that time was to communicate with our child, we were encouraged to use sign language. Since another goal for our child was for her to speak and read English, we were using Signed English as a means of communication. The formal approach to this method is to sign every spoken word. We were using more of a "pidgin" approach, using gestures and facial expressions for signs that we did not know. Hannah was quick to understand and repeat signs. It was obvious that she was starving for communication. I clearly remember her first spontaneous sign. Soon after she turned two years old, we were at the agency that provided her first hearing aids. Hannah pointed to the EXIT sign and signed, "red," for the color of the sign. We were ecstatic that she not only used a sign on her own, but that she had so quickly grasped the concept of colors.

As Hannah's sign language was soaring, we were concerned about the lack of progress she was making with her hearing aids.

It was apparent that she hated them, as she removed and hid them every chance she got. We needed to find out if they were benefiting her, but this seemed impossible. Did she remove them because they were amplifying garbled sound or did she like her silence from her previous world? During this time we were having her tested in a sound booth aided and unaided. Since she was showing more comfort in the booth, her lack of reaction to sounds in the booth was proving that her benefit from the hearing aids was extremely limited. Despite this, Hannah was progressing well with her communication and I recall her first spoken word. She was building a stack of blocks with her teacher of the deaf and the teacher was signing up and saying, “up, up, up.” Hannah clearly repeated “up!” We were pleased with her progress, but it was obvious that her hearing would be severely limited, even with hearing aids.

A conversation that my husband and I began having was that of pursuing a cochlear implant. We learned that a cochlear implant is designed to bypass the part of an ear that does not work, unlike a hearing aid that only amplifies sound. Most children with a profound hearing loss have damaged inner ear hair cells. With a cochlear implant, tiny electrodes replace the job of the hair cells and transmit “sound” to the auditory nerve, which send the signal to the auditory center of the brain. The most successful recipients were people that had hearing before becoming deaf. If a child was born profoundly deaf, the earlier they received the implant also seemed to be an indicator for success in achieving more sound awareness and language. Given that Hannah did not have any spoken language, and that she was now approaching 2 1/2, we were starting to feel pressure to make this decision.

Part of the criteria to be a candidate for a cochlear implant is that proper hearing

aides must have been fitted and tried for the person. We knew that Hannah was not benefiting from the amplification. She needed to be evaluated by the implant center. We chose New York University Hospital. After a 3 day evaluation, Hannah “passed” and her surgery was scheduled for six weeks later. After waiting through a 6 hour surgery, Hannah was implanted, and after another month, she was “turned on.” It was difficult to control our excitement at this time. We had read testimonials and watched videos of children “hearing” for the first time, and we could only believe that would be our result too. We were also worried that Hannah’s past behavior of not cooperating in the audiologist’s room and sound booth may keep her from having the best experience.

At this first appointment, Hannah would receive her external equipment. Once hooked up, the audiologist would program the speech processor according to Hannah’s individual needs. Hannah’s processor is hooked up to a computer to do this. Each time the processor is “mapped,” the threshold levels (when a sound is first heard), are measured along with comfort levels for each of the electrodes. We were told that Hannah would hear a series of “beeps or buzzes” at first. Sent to her too loudly, this could be a very terrifying experience since this would be her first time hearing any sound.

Both my husband and I do not remember Hannah turning or responding to any sound in her initial “turn on.” It was reinforced that her levels were very low since they did not want it to be scary or uncomfortable. We were disappointed, as we were hoping for that incredible moment of sound recognition. What was encouraging was that Hannah did not try to remove any of the external equipment. She carried the processor in a fanny pack and did not seem to mind that

the microphone and magnet were placed on her head. I remember spending the rest of the day in the city, going to Central Park and riding busses throughout the city. We were watching her like a hawk, waiting for her to turn towards any city noise. She did not. She remained calm and determined to do all of the activities she always did before sound.

We returned home and I have to admit we did a lot of the things we were told not to do. First of all, we jumped to look at Hannah every time there was a noise in her vicinity, we kept expecting her to hear and react to sounds. Knowing the anxiety we were under, we probably foolishly expected her to start talking anytime also. We had to make several trips to New York City for follow-ups and each time they increased her power levels, but the idea of making her comfortable with sound was still a top priority.

We continued with her therapy, our home and professional practices. Many cochlear implant and oral method experts encourage parents of implanted children to drop sign language once their implants have been turned on. There is a belief that children will continue to rely on signs and will not learn to make sense of the sounds of spoken language. We were not comfortable with this philosophy. We knew that Hannah needed communication more than ever. We did add more to our home therapy. Along with introducing her to new signs, we added Daniel Ling's *Learning to Listen* sounds to the signs. Along with the sign for the word, we added a sound to support the sign and object. For example, the sound for bus is "buh, buh, buh," so along with pretending to ride in a toy bus, we signed the word and made that sound. This practice helped her match a repeatable sound (that she could reproduce) to an object.

Another addition to our home therapy was the discovery of the Listen Up website

(www.listen-up.org). This site was created by a mother of a child with a hearing impairment, and the sources were extensive. I telephoned her and ordered a series of cards she had created for home therapy. Among these hundreds of cards, are different categories for parents or therapists and children to "discuss." Some of the categories are: "What Does Not Belong," "True or False," "Stories," "Didn't Say it Right," etc. Though I felt that we were spending a lot of time giving Hannah life experiences and explaining to her everything we possibly could, these cards gave practical, fun ideas to help build vocabulary. These cards had pictures or words for the children to point to after they were read a passage. Our goal at this time was for Hannah to gain access to the sounds that her implant provided and to transfer those sounds into language. Playing these games with Hannah and showing her the pictures and words that her sounds were corresponding to, was probably Hannah's first exposure to print besides a story reading.

Soon after Hannah was turned on, we spent one week in Fort Washington, PA, at the Helen Beebe clinic. This program where children, "listen to learn, and learn to listen," is designed for families to spend one week near the clinic so that they can attend daily Auditory Verbal sessions with other hearing impaired children as well as with their own. The philosophy of the Auditory Verbal method is that no matter how great the hearing loss, hearing impaired children can be taught to use their residual hearing through listening only, and become active participants in the hearing world. Within this method, children are given no visual cues or hand gestures. Therapists and parents, when working with the child, cover their mouths so that even lip reading is not a support.

When we participated in this workshop, Hannah was almost three. We were given a schedule that included observing therapy sessions, participating in sessions, and finally being the therapist for Hannah while being observed by trained Auditory Verbal Therapists.

Though this method had successful results with children learning to speak and “hear,” my husband and I felt conflicted with the idea of dropping sign language and leaving Hannah without communication. The therapists were fair in accepting our decision, but did stress the importance of teaching Hannah to rely on the sound that was now being provided by her implant. This proved to be the most important lesson learned from that week at the clinic. One morning, Hannah was in the next room and we were getting ready to go to a session at the clinic. My husband told her to get her shoes, and she came in from the next room, picked up her shoes and put them on! What an incredible joy to realize that her implant was not only providing her with sound, but this was all the proof we needed to see that she could communicate through sound alone!

After leaving the clinic, we developed a natural way of communicating with Hannah. Like I mentioned, we were not comfortable dropping sign language. Hannah lived in silence for almost two years; she was introduced to this communication and was thriving. She loved signing and seemed so happy to finally be able to talk to her family. We did however buy into the idea that the clinic suggested, and did not want her ignoring the sound or word that was accompanying the sign. We started using sign language as more of a support. Instead of signing first to Hannah, we would first say the word and then follow with a sign. We felt that this way she was getting the auditory input, but would not be

frustrated if the word was unfamiliar to her.

People unfamiliar with hearing impairment would not realize that when sounds are introduced to a child, there is no prior relationship. One evening, we were walking in our neighborhood. An out of view dog was barking. Hannah stopped walking, looked around, and signed “dog”. If we had not signed the dog sign while pointing to a picture of a dog in a book, and doing the same with a real dog, her hearing a dog barking for the first time would have meant nothing to her. When Hannah recognized the sound of a dog on her own, it was anything short of a miracle.

We were so pleased with how well Hannah was making the connection with sound and language. As easily as she seemed to pick up sign language, she was listening and communicating by oral language. Hannah’s learning to read was just a long term goal at this time, but by the time Hannah entered preschool at the age of three, we were seeing clear signs of an early reader. Like a typical preschooler, she was recognizing traffic signs, could say and write the alphabet, and she could read and write her name.

In our area, there were very few preschools with programs for children with disabilities. There were two that serviced children with hearing impairments. Our speech therapist and teacher of the deaf worked in one of the preschools, so that was our obvious choice. Hannah’s preschool program was not only for children with hearing impairments, but for children language impairments as well. In her class were several children with Down’s syndrome, two other children with hearing impairments, and one girl with cerebral palsy. It was eye opening to actually be faced with how language impaired your child is. This is not to say that this program wasn’t

outstanding and that all of these children were capable and unique to Hannah's life, but to see that although she had progressed greatly, she was almost 3 years old with only enough sign language to help her survive and some accompanying "sounds."

Luckily, the professionals at her preschool were letting our goals for Hannah lead the way in their approach to teaching her. We couldn't expect them to cover their mouths and talk behind all of the other children, but that is what they did when they were speaking only to her. They let sound be the first indication of communication. Looking back, it doesn't seem like it took too long before Hannah was relying on sound first and sign and lip reading for support. Of course it was a long process since we were letting a natural progression take place. On top of all this new technology and therapy that was being introduced to Hannah, her life was changing because she was now a preschooler. She was making friends, learning about the calendar, and going on field trips. She needed to communicate with peers, teachers, and her family.

Now that it seemed apparent that Hannah was cognitively and auditorily succeeding with the implant, we decided to put her into a typical preschool along with her hearing impaired program when she was four years old. The next year she would be entering kindergarten and for us that meant the "real world." She needed to be academically prepared for the next stage of her education.

This preschool setting was similar to a Montessori school. There were three separate rooms with three separate themes: computer, activity, and dramatic play. The children had very few "assignments" to complete, and came together for calendar and sharing time. The rest of the time they were allowed to roam and choose how they spent their time. This school proved to be successful for Han-

nah. Because she was still mainly non-verbal, she could still parallel play wherever she wanted to go. This preschool was located in our town, so we knew that she would be attending kindergarten with some of the children in her class.

The summer leading up to Hannah's first year of kindergarten was anything short of excruciating for my husband and me. In June of that summer, she was screened by a team of kindergarten teachers and speech therapists. They believed that because of her late birthday, and especially her speech impairment, that she would be best suited for an early kindergarten class. On the outside, we were telling her how exciting kindergarten would be for her. On the inside, we were both feeling nervous that we were pioneering a program for our area, and the setting may not be right for her. Looking back, of course we were overreacting. Even though she had been to two preschools and had not only adjusted, but excelled in both settings, we were worried that this was the first real test of her development in a mainstreamed school setting. We worried that this next year could lead to an alternative setting or even a move for our family to a city with more services for the deaf.

Hannah was in an afternoon kindergarten class. We had prepared her the best that we could, so she had been to the room and met the teacher several times. As I walked her to her room, she dropped my hand as soon as she entered her room. Part of me felt as if I was letting go of my baby, but mostly I felt secure that this was going to work. I was in awe of my child's confidence and bravery.

In 2005, Hannah is a fully mainstreamed third grade student. Her teacher states that she is an exceptional student. She

has above average skills in both reading comprehension and written expression. She is on a swim team and plays violin and piano and she has many friends. Her parents continue to be in awe of her courage and spirit.

In 1997, our son Hughie was born. Hughie is also profoundly deaf. He received a cochlear implant six months after Hannah's surgery. His therapies, programs, spirit, and achievements mirror his sister's. He is also a gifted student whose reading, writing, and math skills are several years ahead of his age.